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Marcia Dufore interview for the Lest We Forget Collection of Oral Histories

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Marsha

Marsha Dufore

~~MARSHA GALORE~~

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Jeff: It's July 14, Bastille Day, 2003 and this is the Lest We Forget series taping in Akron. I am interviewing Marsha GaFore and Terry Alexander. Marsha, you are the sister of Jack. May I ask your age Marsha?

Marsha: Almost 50.

Jeff: And how old is Jack?

Marsha: 54.

Jeff: Would you tell us the circumstances about life at home with Jack before he was institutionalized?

Marsha: We grow up in a suburban neighborhood. He has cerebral palsy. He was four years older than me and my parents were told at a very early age that he would never walk. He was quite a determined young man and at a certain point began walking with crutches and at a certain point, probably after I started stealing his crutches, when I was playing with him he threw his crutches away and began not really walk kind of ran without crutches. Went to public school in special ed. classes, went to high school, just a normal family situation except that he went to a lot of therapy as he was growing up.

Jeff: What were the circumstances that led to your parent's decision to send Jack to live in an institution?

Marsha: When Jack was in high school there were only two tracks for someone with special needs. One was to go the vocational route; the other was to graduate as a regular ed. student. Jack because he had cerebral palsy and cognitive impairments the school system couldn't figure out how he could go their vocational tracks. So at that point they said that he would not be able to graduate which hurt him tremendously, still hurts him. But my parents at that point couldn't figure out what to do. I think he probably had some kind of a breakdown at that point, cried and screamed most of the time. They then began to look for what other options there were. At that point there weren't group homes and they chose Apple Creek State Institution.

Jeff: What year?

Marsha: My parent chose to institutionalize him in about 1966.

Jeff: Do you remember any of the rationale that they were told about what that was like or the benefits or why that would be a good choice?

Marsha: They did visit Apple Creek and thought that it would be an okay choice. What I learned much later in my life was that my father had a sister with downs syndrome who was not institutionalized as he was growing up. He had an older sister who was responsible for her care. She received very little training. She was behaviorally very much out of control. His sister ended up committing suicide. My father, until his dying day, blamed his mother for not doing something about his special needs sister such that the rest of the family could have a life. So when my father saw my brother losing it, he said my family will not be destroyed again. Basically I think that was the irrational rationale that went into spearheading that decision.

Jeff: Do you remember what happened, the details concerning Jack's move from home to Apple Creek?

Marsha: Just remember that he went. We visited every week end. So we were back and forth quite a bit. He was in Wooster, we were in Cuyahoga Falls so there was—it's about an hour's drive. We were regularly there. He had regular contact with my family. My mom was a very strong advocate for him. But I don't remember exactly how the first day went or how that happened.

Jeff: What were the visits like?

Marsha: Those are things that are very strong in my memory. At that point everything was a locked unit. He was in a locked unit and I can remember going up to the main building and the clanging doors and the ring of keys and them letting him out and then we would go out into the grounds and visit and we would go into the town. There was an apple restaurant that we use to eat a lot and we would just have a nice visit. Then we would drop him back off again and they clang those doors shut and the smell. Those were the things I remembered as a kid.

Jeff: Talk about the smell.

Marsha: It smelled like urine, smelled like too many people living together and that's where we left him every time we dropped him off

Jeff: Were you allowed onto the ward?

Marsha: I have a vague remembrance of going onto the ward and lots of beds. I also remember other parts of the institution where they were more like cells. I don't know if I visited those when I visited with him or when I was in college and was just volunteering or visiting the center but I do remember just seeing horrible conditions.

Jeff: So when you say cells you speaking of jail.

Marsha: It was like a jail cell for people that were very severely impaired. Jack seemed to be well liked and seemed to have greater freedom than some of the other people there. He got to do the laundry and so he after a while got to go in and out and had privileges that others didn't. And at some point didn't have to be locked in like others. But my initial remembrance is where he went in and that door clanged behind him.

Jeff: Did you ever visit him on the ward, stay there with—

Marsha: No, we always went out. We went and got him and then we went for a walk. The grounds were beautiful and we would walk the grounds or go out to eat but we didn't—you wouldn't want to visit inside.

Jeff: Did you ever go into that room at all behind the door?

Marsha: I think that's where I saw these rows of beds behind that door. But again it's more of a traumatic memory than it is a clear detailed memory.

Jeff: When Jack would be brought out to you would he be wearing his own clothes?

Marsha: There were always problems with clothes. We would send certain clothes to him. He would sometimes have those clothes and sometimes have somebody else's clothes or sometime clothes would just disappear. When he was in charge of laundry he had a little more control over what might be his or not his. They were marked but clothes were always a problem.

Jeff: How did Jack's behavior change when he was sent to Apple Creek?

Marsha: Jack always remained a nice person. He did not seem to be affected by his surroundings in the way of being depressed or take on any nasty characteristics. I think he lost some of his independence and he was fairly submissive but he stayed extremely friendly which is, I think, why he was well liked and received some privileges. Jack has always taken the very best that he can out of every circumstance and just kind of rolled with the punches and he continued to do that. I never saw any bitterness. I never saw any aggressiveness and I never saw any depression. I remember feeling very distant from him at some point when I was in high school saying to my mom I don't feel like I really know my brother any more. He remained a very nice person.

Jeff: You were 13 and Jack was 17 when he was at Apple Creek. Did you ever know anything or experience in a second hand way anything about the treatment of others with whom Jack lived?

Marsha: Jack really didn't talk about the treatment of others. My only impression was the clanging of the doors. The fact that people were locked in and then a visit to the

developmental center and I can't remember when this was but seeing people actually with bars and like a prison cell, just being stunned by that.

Jeff: Was Jack medicated?

Marsha: No, never medicated.

Jeff: Did Jack smoke?

Marsha: Jack never smoked, didn't take up that habit because others around him smoked, never smoked.

Jeff: Did you ever see people walking on the grounds with staff?

Marsha: I did see people walking on the grounds. The one occasion that I can remember that sticks out for me probably because I was a kid and I was scared was we were walking on the grounds or sitting or having a picnic or something on the grounds and there was another fellow that was just walking and he started to chase me and I got scared because he just seemed weird. So I said times and walked back to my mom and he went for it. I thought I was pretty clever. But he was obviously out there on his own with no staff with him at that point and I was sort of fending for myself.

Jeff: Do you remember the nature of the buildings?

Marsha: As Jack was there for a longer time there were some cottages and Jack eventually lived in a cottage but for most of the time he was there he was in this big main building and there were big clangy doors on both sides of the entrance. That's where he lived and he kind of lived down in a lower section of that building where there was actually a door that he could go out of at one point in time—old building that stank.

Jeff: So Jack lived on the ground floor.

Marsha: Yes, Jack lived—there was a main floor I think there was even a second floor but there was a main floor and then there was like a lower floor that actually had an entrance on one end that he eventually lived in.

Jeff: How long was Jack at Apple Creek?

Marsha: He was there from 1966 to—he went from there to Cleveland Developmental Center I think in the late '70s so 15 years or so.

Jeff: How long did he live at the Cleveland Developmental Center?

Marsha: Only about three or four years and that was a much worse experience actually in my family's mind and in Jack's mind, I believe than Apple Creek. Maybe because we had gotten used to Apple Creek and actually Apple Creek had improved in terms of his privileges and his care over the years. Cleveland he had to walk somewhere to do his laundry no matter what the weather was he was walking on city streets carrying his laundry and his balance was not great. It was a pretty ugly picture. He lived on the institutional grounds initially and then they had these cottages that he was allowed to move into and they told my parents that he could move there but only if they pay his—

Jeff: Was he living at the Ohio Residents Association?

Marsha: He lived there maybe with her one time. But there were some houses around the grounds and they moved him there even without telling my parents and then suggested to my parents that this was a better setting for him but if he wanted to stay they were going to need to pay his room and board. My mother considered that to be blackmail and called her legislature and raised quite a stink. I think somebody there got fired as a result. But Jack got to stay in that residence and my parents did not pay his room and board. I think that's probably what really got my parents thinking that there must be something better than this and started looking into residential options in our community.

Jeff: When you say that the Cleveland Developmental Center situation was worse for Jack can you describe in what ways.

Marsha: It was worse in that they seemed to care less. There was the situation of the room and board. There were just constant communications that seemed like blackmail. If you want

him to eat well then you pay for it. If you want him to have a life then there is something you're going to have to do to make that okay. The treatment, the people seemed less caring. The fact that they would have him with his mobility issues walking on a busy street trying to carry his laundry to do his laundry was just unfeeling stupid setup for them to put up. But that's how they did it and they said well this is independence. And my parents said this isn't independence this isn't transition to community this is just stupid and not caring. So they became very angry and frustrated and began looking for other things for him.

Jeff: Do you know whether that situation was for a profit using some of the grounds at CDC.

Marsha: I don't believe that was a for-profit I thought that was all a part of the same set up. But it could have been. It seemed to me that the woman who was in charge of the Cleveland Developmental Center was the woman who was saying these are the rules of the game, play them or he goes back into the institutional setting.

Jeff: This was in the late '70s early '80s.

Terry: Late 70s.

Jeff: When you would be visiting with Jack and it was time to go back whether it was at Apple Creek or CDC how did Jack respond to that?

Marsha: Jack would just go back to where he was supposed to go and we would give our hugs and he was very passive about—this is my life and he didn't cry. This is my life and I'll see you soon and that was that.

Jeff: Did he ever come home?

Marsha: Oh, yes, he came home for all the holidays and any special occasion. We would visit him or we would bring him home.

Jeff: When he was at home say for the holidays and there were gifts given was he able to take the gifts back into the institution and maintain them?

Marsha: I have no idea if he was able to maintain the gifts we gave him. He was certainly given gifts. I can't remember whatever happened to the gifts we gave him. If it was clothing it probably disappeared. But I can't remember about other things. I can't remember radios or anything like that, probably kept those at our house. He had a room at our house and he probably kept those things at our home.

Jeff: Do you have any knowledge or sense of what Jack's dental care or medical care was about during those years?

Marsha: Jack's dental care, he fell a lot. He fell a lot so he's lost parts of his teeth and we've talked in his later years about whether he'd like to have those pulled and have some false teeth but at the time that didn't seem to be an option at all; maybe because he would have fallen again and the same thing would have happened. My parents were involved in that decision about his teeth. Medical care seemed adequate but my parents would also take him to the doctor themselves when he came home if they felt the need to do that. My parents were always very involved in making sure that he got what he needed.

Judy: Could I ask a question here Jeff? Going back to the word you used earlier about the irrational rationale and your father's wanting to protect his family from what he had seen happen to his paternal family, what do you think was there a reaction in the family though even though it might not have been as destructive as he saw with his sister. What was the impact on your family in not having Jack there? Did you see reactions from your family? Did it put roadblocks in your family or did it cause disruption in your family or did it seem like that was the right thing and you went on

Marsha: Well, I was only 13 so I don't know if I knew all the reasons why people were making the decisions at that time. I know that Jack was so upset and I remember his screaming and I remember his skin looking like something was crawling underneath. He was very, very upset. I think my parents were afraid. They didn't know what else to do and at that

time there were no group homes. There were no vocational programs. They saw no options to stop this and felt that Apple Creek was their only option.

Jeff: Judy, maybe what you were asking was once a decision had been made and once Jack was sent to Apple Creek and for the intervening years he was institutionalized what was the effect on the family?

Marsha: I would say that the impact on the family over the course of years that Jack was gone a lot was part of our life moved to Apple Creek and we spent almost every week end visiting Jack. I became very familiar with all of the things that were in place around people with disabilities. My mom spent a tremendous amount of time advocating for him and that became a focus of our life and I became to some extent an only child as well. So there was definitely, even though we visited him, he wasn't living with me as a brother and I began to see him as somewhat of a stranger. At some point I remember driving in the car with my mom, crying and saying I don't know if I know him, how do I know if I love him if I don't know if I know him which may be something that siblings experience any way. But I certainly experienced that. I didn't know if I knew my brother.

Jeff: The decision to move Jack from CDC back to the community, do you remember the process, the thoughts, the feelings?

Marsha: I remember that my parents began to explore because they were so very frustrated with Cleveland Developmental Center. At that point there were some fellows from Ardmore that were I think had worked at CDC or somehow or another they made themselves known to families and so my parents talked with them and then Hope Homes was an agency that was also supported by my parent's church. So there was affiliation there and my parents began exploring the options with Hope Homes and felt very comfortable with Hope Homes and at that point met, I think, probably still the executive director, Vince ReBino, and shortly after that met Terry Alexander and her husband who became my brother's first group home staff. That time it was house mom and house dad and they lived there and there were eight other guys in the house or something like that. But it was a real transition back to the community for Jack.

Jeff: What year was that?

Marsha: In 1978 Jack moved back to our community in Hope Homes, a group home.

Jeff: How far was the home from your house?

Marsha: It was about maybe ten miles from my house.

Jeff: Do you remember the experience, what it was like those first months?

Marsha: Again I was away at college so I was in and out of the situation but my parents were very pleased. Jack was close to home. The staff at Hope Homes really liked him so again he was in a situation where he was appreciated, where he had freedom. It was a rural setting. He could walk. He could do what he wanted to do. There was frequent contact with my family and my mom was just finally feeling good again about where Jack was and how he was being cared for.

Jeff: What was your first contact with Jack once he was settled back into Hope Homes?

Marsha: I would visit his house. He would come home for holidays and not so much week ends, well week ends he would come home or I would go there. It was a back and forth thing. We would go putt putt together or he'd come home for the week end and we'd just do stuff.

Jeff: How did you feel about the change and how did Jack feel about the change from your perception?

Marsha: Jack felt very good about his new circumstance. I felt great about it. My mother was relieved and felt that she could trust the people that were caring for him which was very, very important to her to be able to trust them.

Jeff: How did Jack's quality of life improve?

Marsha: Jack started being able to do stuff on his own. He was able to help choose the meals that they had. He was able to be involved in grocery shopping. He was able to cook some although there were a lot of people in the house so they kind of took turns I think with the cooking. He shared his room with one other person instead of large numbers of people. He would just go out of the house on his own. He had a three wheeled bicycle that he would go for rides on and he just had freedom and independence and started doing the things that he was able to do when he lived with us, had not lost those skills but had no reason to exercise them in an institutional setting.

Jeff: Personal possessions, clothing.

Marsha: Started accumulating, lots of possessions and lots of clothing. I was over in his bedroom not too long ago and he has more stuff than there is room for. They were encouraging him to clean out his closet. He's got his own TV now and he's got a closet full of clothes and a VCR and a camera. Pretty much whatever he wants, he can buy whatever he wants because he works and earns money and takes vacations and has a life.

Jeff: I think we should shift the focus to Terry and if you want to add in feel free.